



The Parkinsonian

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NW PADRECC

Parkinson's Disease Research, Education & Clinical Center



Patching Up PD

By Jeff Kraakevik, MD

The doctor enters with a flashing gizmo and waves it over your arm. He looks concerned and pushes a button on the wall. The machine that goes "ping" slowly rolls into the room. It flashes

more lights, and goes "ping". The doctor looks you squarely in the eye, and says, "Well, that was close, but we took care of all your problems. We'll see you again in 6 months."

We all have visions of medicine in the future made up primarily of scenes from science fiction movies. Who wouldn't want to throw away all their pills, and be treated in a big tub of goo like Luke Skywalker in "Empire Strikes Back"? Well, some of those visions of futuristic medicine are becoming a reality. No, we are not talking about using goo to treat Parkinson's disease, but we are talking about a new way to replace some of those pills you take with something a little easier to swallow.

In fact you don't have to swallow this stuff at all. The medicine is called rotigotine (Neupro™), and it's interesting in that it comes as a patch you put on one time per day. Rotigotine is really not so new in how it acts or what it does to the symptoms of Parkinson's. In fact, research which was partly conducted through the PCO at OHSU revealed that rotigotine is very similar to the already available dopamine agonist such as pramipexole (Mirapex), and ropinerole (Requip). People with Parkinson's disease treated rotigotine in these

studies experienced similar decrease in Parkinson's symptoms to what was previously shown with these older medications. Like pramipexole and ropinerole, rotigotine was used both when it was taken by itself early in the disease, and when added to Sinemet later in the disease. The good news is that rotigotine maintained fairly even blood levels during the day, and it also fairly quickly gets out of the bloodstream if the patch is stopped for any reason. The research patients also experienced very similar side effects to those seen with pramipexole, and ropinerole including the possibility of nausea, confusion, excessive sleepiness, and hallucinations.

So although rotigotine does not quite match up to a machine that goes "ping", it does provide a look into the future of medicine. No, this medicine will not likely replace Sinemet as the most effective form of treatment of Parkinson's disease. And, no it will not likely be much different from pramipexole or ropinerole. But it will provide an option for people who have early disease and don't want to have to bother with remembering to take pills three or four times per day. It will likely also be useful in people with swallowing troubles. Just like with

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What's Inside

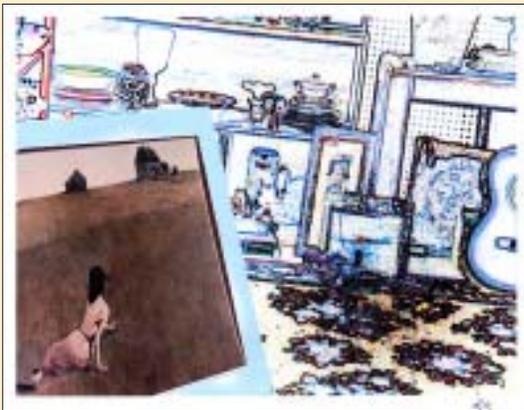
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Patching Up PD *(continued)*

Featured Artist

After being diagnosed with Young Onset Parkinson's Disease in 1990, Dan North began making art as a way of relieving depression during down-times. Through his creative explorations of digital collage making, painting, and writing, Mr. North discovered several things about himself, namely that he is ambidextrous, and also overcame challenges such as color-blindness and tremors. He encourages others to experiment artistically on those down & out types of days and offers the following advice: "Give it your best shot and have some fun!"

Mr. North served in the Air Force and has been treated for Parkinson's at the Portland VA for about a year.



Untitled



Passing Time

If you have an artistic talent and are seen in our clinic for PD, we invite you to share your work and tell your story through our newsletter! To inquire, please see the contact info on page 4.

any medicine, you need to talk to your doctor about whether this medicine is right for you. You should also know that rotigotine has not yet been officially FDA approved, and may not be available until some time next year. All that said, it will be nice to have a piece of the future today.

Dear Vicki...

I am the primary caregiver for my spouse who has advanced Parkinson's. Her disease has progressed to the point where I have assumed most of the household responsibilities, as well as managing our legal and financial affairs. I am feeling overwhelmed, tired and incredibly sad. I hesitate to call our sons, but I feel as though I am sinking.

You and your spouse are experiencing major changes in the roles and responsibilities that likely have been established for a long time. These roles are not easily set aside, and it is common to have feelings of grief, including sadness, guilt, reluctance, love, anger, anxiety and a sense of helplessness. Sometimes distress is heightened because you are not only dealing with changes in roles, but also the need to learn new tasks. Learning a new responsibility, such as keeping the checkbook or washing clothes, also involves energy and effort. This can be difficult when you are faced with the many day-to-day needs of the person with PD, yourself, and your family.

It is important that others give you encouragement and support, help with work, and/or share the responsibilities. The first step in getting the support you and your spouse need is recognizing the distress that you are experiencing. It is hard for family members who do not share the day-to-day experience of living with a person with Parkinson's disease to know what it is really like or how you are feeling unless you tell them. Now is the time to start an ongoing dialogue:

Dear Vicki... (continued)

- Set aside fears about “burdening” your children
- Have an honest discussion with your family about what is happening at home
- Create an atmosphere that focuses on comfort, not confrontation
- Be open with your children about both of your abilities, wishes and needs, including what your wife is still able to do and what is too difficult for her
- If necessary, engage a counselor or a legal/financial professional to facilitate family discussions or issues that arise
- Consider community resources outside of home

By openly sharing your concerns, adult children and parents can learn how to face the challenges *together* without creating assumptions that your kids are “too busy” or do not want to help. If your children are truly unable to help with any of the responsibilities of caring for your wife, seek out other sources for support by talking with the local Parkinson’s support group association, a social worker, or the local Area Agency on Aging office about resources available in your county.

Given that some family relationships can be complicated, or family members have different ideas about what should be done, you might want to seek out a third-party facilitator, such as a therapist, a trusted family attorney, or a financial planner who already is working with either the parents or the children. Be patient, as most issues aren’t going to be resolved with one meeting.

Recognize that role changes are ongoing and as the illness progresses, you may have to continue to take on new responsibilities. Each time, you will probably experience some of the feelings of sadness and of being overwhelmed by your job. This is part of the grief process in a chronic disease. Talk over your situation with other families of people with PD. You may reach a point where the extent and demands of your job as caregiver are exhausting you. You need to be able to recognize this and to make other arrangements when that time comes.

Sincerely, Vicki

Education & Outreach



Speaker Gordon Campbell, FNP

“Fatigue in PD” Event a Big Hit!

Almost 80 vets, caregivers, and providers attended PADRECC’s latest talk, “Fatigue in Parkinson’s Disease” last month. Fourth in a year-long series of discussions about PD and related

issues, this was our best-attended event to date. Gordon presented the impact of physical and mental fatigue on PD patients, how it disturbs sleep and initiates depression, and how fatigue can be treated.

Videos and supplemental handouts are available for those who missed Gordon’s talk. Contact Jeremy at (503) 721-1091 to request information. See ‘Calendar of Events’ on pg. 4 for future talks.

Online Curriculum Instructs in Care for Parkinson’s People

New to Parkinson’s? Or simply looking to learn more? An online curriculum, the Parkinson’s Educator, can help. Developed for paraprofessional caregivers, the Parkinson’s Educator is also beneficial for family caregivers or anyone looking to better understand Parkinson’s disease. The curriculum, which highlights “best practices” in caring for Parkinson’s people, was written and reviewed by a team of Parkinson’s specialists. The curriculum can be explored at www.parkinsonseducator.org. There is no charge to complete the modules.

Research Opportunity!

The PADRECC is offering a chance to participate in several different research studies related to PD. If you are a patient in the PADRECC movement disorders clinic with PD and are interested, please contact Susan O’Connor at (503) 721-1091 to see if you qualify.

Calendar of Events

Upcoming classes, support groups, and other events related to movement disorders

“I Can’t Remember and I’m Feeling Down, So I’m Going to Vegas: An Overview of Cognitive Changes in Parkinson’s Disease”
Jeff Kraakevik, MD
Friday, March 24, 10-11:00 am **date change*
Portland VA, Auditorium **venue change*

Challenges & Champions: Summit on PD
OHSU’s Parkinsons Center of Oregon (PCO)
Thursday, April 13, 2006, 1-5:00 pm
Red Lion Columbia Center, Kennewick, WA

Riding the Waves of Parkinson’s Disease
Parkinson’s Resources of Oregon (PRO)
Sunday, April 30, 2006
Newport, Oregon

“Update in Research in PD”
Kathy Chung, MD
Thursday, May 11, 10-11 am
Portland VA, Auditorium

Strike Out Parkinson’s Bowl-a-thon
Benefiting Parkinson’s Resources of Oregon & Parkinson Center of Oregon
Saturday, May 20, 2006, 10:30 am-1:30 pm
Sunset Lanes, Beaverton, OR
Call the PADRECC to be part of the VA team

Huntington’s Disease Symposium
Co-sponsored by PADRECC & PCO
Sunday, May 21, 2006
Vey Conference Center at OHSU

* *Event contact info:* **PADRECC:** 503-721-1091 **PRO:** 800-426-6806 **PCO:** 503-494-9054 *

To receive the *Parkinsonian* by e-mail please forward a request to nwpadrecc@med.va.gov. Call 503-721-1091 to be removed from our mailing list.

If you have a question or a creative contribution you would like to submit for the newsletter, please send it to the Portland address listed below.



Attendees at recent talk, “Caring for the Caregiver”



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